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Why Having a Mental Illness Is Not Like Having Diabetes

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A number of times during the course of my illness I have been told by health professionals that it is useful to think of having a mental illness (in my case schizoaffective disorder) as having a lifelong disease that requires lifelong management and drug treatment—in fact, just like diabetes, a well-known disease affecting a large proportion of the population. Diabetics, so the story goes, need to accept that they have an illness that will require treatment for the rest of their lives; and if they continue the treatment, they will maintain their health insofar as this is possible, while if they discontinue treatment, they will suffer dire consequences, including blindness, loss of limbs, diabetic coma, and so on. Looked at in this light, treatment of a mental illness is just the same; if medication and other treatments are continued, the prospects are relatively good, and if not, the prospects are dire.

This story is common among health professionals who treat those with mental illness, but it also occurs in some medical research in which schizoaffective patients have been explicitly compared with diabetes patients. In a series of studies a team based in Lund, Sweden, took schizoaffective patients and compared their social networks and background factors.[1,2] The rationale for making a comparison between schizoaffectives and diabetics is as follows: "From a medical and psychological point of view there are similarities between diabetes and schizoaffective disorder. In both diseases you may prevent a relapse by taking medication (insulin or lithium) and the risks of pregnancy and delivery are greater than for healthy women. Further, the chances that a child to a parent with diabetes or schizoaffective disorder will subsequently develop a diabetes or a schizoaffective disorder are considerable. Thus, the medical and mental strain caused by diabetes and schizoaffective disorder to some extent may be the same.[2(p906)]

I would like to spend the rest of this article showing why this parallel, so frequently made, is ill conceived and unhelpful.

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Hospital Experience

A diabetes patient in hospital can expect a clean, hygienic ward peopled by staff who treat the patient with respect, as an equal, who explain the illness and the treatment regime, and who co-opt the patient as an important agent in his or her own recovery. A psychiatric patient, however, might well find a ward that is rundown and peopled by staff who do not seem to have the same expectations of respect for patients and of a generally good professional working relationship between staff and patients. A psychiatric patient might instead, as I did in one of my hospitalizations, find staff who avoided talking to the patients as far as possible and whose only interaction with patients was to give commands.

As a diabetes patient, one would certainly not expect violence or abuse from fellow patients; and if this did occur, one could expect a swift reaction from the staff. However, as a psychiatric patient, violence from other patients is at times a real risk, and one that staff might seem to regard as inevitable.

A diabetes patient would certainly not expect to come out of the hospital experience feeling belittled and demeaned, whereas this is something that has been reported by psychiatric patients; and certainly it was my own experience in one hospital.

Finally, in a diabetes ward there is no sense of being in a prison, even though diabetic patients, just as much as schizoaffective patients, are necessarily confined to the ward for their health and safety. Mental patients in hospital, by contrast, frequently report feeling as though they were in prison; certainly during one of my hospitalizations I spent most of my time trying to devise ways to escape.

Attitude of Family and Friends

Schizoaffective disorder rips straight into the heart of the family, causing shame, anger, guilt, and self-blame from parents and siblings, as well as casting blame on the patient. Parents ask, where did I go wrong, and patients ask, if I had had a different upbringing could I have avoided this disease? With diabetes, however, there is no sense of blame, guilt, or shame; rather, people hear the diagnosis, learn (perhaps over time) about the condition, and come to accept the limitations of the condition.

After receiving a diagnosis of diabetes, a person could expect that their friends, on inviting them over for dinner, might inquire how they could best fit in with the patient's new diet, if that were necessary. However, after receiving a diagnosis of schizoaffective disorder, a patient would be waiting a long time for someone to ask how he or she could fit in with the sickness. This is a pity because there are many very simple ways to make life easier for those who suffer from psychosis and other mental illness problems. In my own case, for purely psychotic reasons, I would love to be assured that there would be no electronic beeps in any house I was going to visit. However, I find it difficult to imagine asking even close friends to turn off any electronic beeping machines when I am coming over; the request would be embarrassing and weird. It is not confronting to conform to a diabetic diet, but it is confronting to adapt to a psychotic patient's needs.

With diabetes, there is no stigma. People are not afraid of a diabetes patient. A diabetes patient would probably feel free to tell anyone that he or she has diabetes, without expecting possible rejection or shunning. I have frequently been warned by health professionals never to tell anyone, apart from close family, the name of my sickness. Diabetes patients can even tell an employer about their disease, whereas schizoaffective patients would be most unwise to.

Even if the general public does not know the causes or exact effects of diabetes, knowing only perhaps that it is something to do with sugar in the blood, which means that someone with diabetes has to be careful what they eat, their ignorance does not lead to fear and ridicule. Diabetes is in fact quite easy to explain to a layperson. Schizoaffective disorder is very hard to explain to a layperson. My own child is getting to be old enough where she will soon need an explanation from me of what exactly my sickness is and why I need to go to hospital now and then. Such an explanation for a diabetes patient would be easy. For schizoaffective patients it is very hard.

In the media diabetes generally receives an impartial, unemotive treatment. I have never seen schizoaffective disorder referred to in the media (another problem contributing to ignorance in the general public), but its close relative schizophrenia is almost universally dealt with in simplistic, lurid, and often violent terms—in any case generally with more hysteria than information.

The Disease Course

The course, and consequences, of the 2 diseases are very different. Diabetes does not get out of control and make a person do things for which they could be civilly or criminally liable. Diabetes does not gradually erode a person's ability to think and reason or leave one unable to decide what is true and what is not true in the world, crippling his or her ability to act as an independent adult. Diabetes does not affect the very way people think, who they are, and how they operate socially, professionally, and within their family. Schizoaffective disorder does.

Treatment

Diabetes medicine does not change who a person is; it does not turn one into a zombie, negating the highs as it flattens out the lows; it does not change the way one operates or, in fact, change what it is to be that person. Medicine for schizoaffective disorder does.

Diabetes treatment does not require the same sacrifice of personal privacy that nonmedical treatment for schizoaffective disorder does.

These facts, each one perhaps small in itself, combine together in schizoaffective disorder to contribute toward an insidious erosion of the sense of self that is compounded by the action of the disease itself and the side effects of the medication. I therefore reject the analogy of schizoaffective disorder as being like diabetes. If I could choose a replacement analogy, I would say schizoaffective disorder is like a whirlwind: it comes out of nowhere, strips you naked and sucks you dry, and swiftly vanishes, leaving you empty and shaken but alive, wondering if it really did happen and whether, and how soon, it will come back again.

References

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